Voluntary Assisted
Dying Review Board

Report of operations

2018-19



This report is the first from the independent Voluntary Assisted Dying Review Board.

It details:

- key work undertaken by the Board to prepare for the Voluntary Assisted Dying Act 2017 coming into effect on 19 June 2019
- activity under the Act from 19 June to 30 June 2019.

By law, the Board is required to report to Parliament every six months for its first two years.

The next report will be tabled by February 2020 and will cover the reporting period 1 July to 31 December 2019. After the first two years, the Board will report each financial year.

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Foreword

The Voluntary Assisted Dying Review Board was appointed to independently review voluntary assisted dying activity in Victoria. This is an important role in assuring the community and the health professions that voluntary assisted dying is carefully monitored, assessed and independently reviewed.

While this oversight role is the purpose of our being and our independence, in reality there are several Victorian agencies who each play a role in making sure voluntary assisted dying is safely administered. A big focus for our first year has been to ensure all these agencies were working together and understood their obligations come 19 June 2019.

My sincere thanks to Julian Gardner and the Voluntary Assisted Dying Implementation Taskforce, who helped us clarify the Board's legal powers and jurisdiction, manage any potential conflicts of interest, and develop the suite of mandated forms required under the Act.

Thank you also to the many agencies who worked with us to agree on streamlined referrals and information sharing. This includes the Department of Health and Human Services, Births, Deaths and Marriages, the Coroners Court of Victoria, the Victorian Civil and Administrative Tribunal, Victoria Police and the Australian Health Practitioners Regulation Agency.

Balancing access and rigour

There are many checks and balances to the Act, which was designed to be the safest in the world.

This Board has worked hard to translate the complex Voluntary Assisted Dying Act into forms that are easy to understand and processes that are easy to follow for both patients and doctors, but still rigorous enough to reassure the wider community.

We were proud to see this work culminate in the launch of the Voluntary Assisted Dying Portal – an online platform that can be accessed by doctors, the statewide pharmacy service, drugs and poisons officers and the Board to monitor and review each case. The feedback so far has been positive.

We will continue to report openly and transparently

In our first public report, we have covered our largely administrative activities over the past 12 months.

Covering only 11 days of the operation of the Act, we are not able to report on any activity other than the number of doctors trained in our portal.

We will give you more detail in future reports, and provide you with all the detail we can – whilst protecting the privacy of all involved by ensuring it does not identify patients, their families or medical practitioners.

Help us to improve voluntary assisted dying

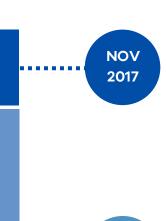
This Board is more than happy to receive any feedback, and has built improvement opportunities into our processes and data collection.

Betty King

Chairperson

Voluntary Assisted Dying Review Board

Milestones



Voluntary Assisted Dying Act 2017 is passed by Parliament



The inaugural Board is appointed by (former) Minister for Health Jill Hennessy



The Board meets for the first time



The Board launches the Voluntary Assisted Dying portal

The Department of Health and Human Services hosts the Voluntary Assisted Dying Implementation Conference, attracting 450 people over three days

The Board finalises its case review process to assess compliance with the Act

The Board finalises process to monitor medication in the community

The Act commences

By 30 June 2019

doctors completed or were in the process of completing online training

Note: More detailed data will be reported in the future.

About the Board

The inaugural Voluntary Assisted Dying Review Board was appointed on 1 July 2018 to independently review voluntary assisted dying activity in Victoria. It was established 12 months before the full commencement of the Act to allow time for the Board, health services, doctors and the community to prepare.

The role of the Board

The Board monitors and reports on all activity under the Act to ensure compliance with the law. It retrospectively reviews every time a person is assessed for voluntary assisted dying or accesses it.

It is important to note the Board does not have an investigatory or punitive role, or an approval function. Instead, the Board may refer any identified issues to the State Coroner, Victoria Police, the Australian Health Practitioner Regulation Agency or other appropriate investigator or regulator.

For more detail on the Board's role and functions, see Appendix 1.

How the Board operates

The Board meets monthly, presided over by the Chairperson or Deputy Chairperson.

For more detail see the Board's terms of reference at Appendix 2.

Administrative support

Safer Care Victoria supports the day-to-day operations of the Board. This includes:

- receiving the required forms
- corresponding with medical practitioners and other bodies
- preparing reports and case reviews for the Board to consider.

Membership

The Board has 13 members who have been appointed for a six-year period.

Inaugural members represent a wide range of expertise and skills to help perform the functions and duties of the Board.

2018-2024 members

- Chairperson Justice Betty King retired Supreme Court judge
- Deputy Chairperson Charlie Corke Intensive care specialist
- Margaret Bird Consultant physician in geriatric medicine
- Molly Carlile AM Senior healthcare leader and palliative care expert
- John Clements Consumer and IT consultant
- Sally Cockburn General practitioner (VR) and broadcaster
- Mitchell Chipman Medical oncologist and palliative care physician
- Jim Howe Neurologist
- Danielle Ko Palliative care physician
- Margaret O'Connor AM Emeritus Professor of Nursing
- Paula Shelton Lawyer
- Nirasha Parsotam Medication safety expert
- Melissa Yang Respiratory and sleep physician, consumer

Activity under the Act

The Voluntary Assisted Dying Act was introduced on 19 June 2019, allowing eligible Victorians to access voluntary assisted dying. Prior to the Act coming into effect, the Board used its first year to establish clear processes for both the Board itself, and voluntary assisted dying.

Finalising processes for voluntary assisted dying

To ease referral processes and information sharing, the Board worked closely with the Department of Health and Human Services, Births, Deaths and Marriages, the Victorian Civil and Administrative Tribunal, the Coroners Court of Victoria, Victoria Police, and the Australian Health Practitioners Regulation Agency.

This ensured all agencies involved in the safe operation of the Act were clear on what information they could receive, when they would receive it and what they needed to do with it.

Checking each case complies with the Act

To ensure each case is thoroughly and consistently reviewed, the Board established a process to check each case reviewed complies with the Act.

The Board follows a structured case review template at their monthly meetings. This process helps the Board identify when it may need to:

- refer any potentially non-compliant matters to external agencies
- report concerns to Parliament, the Minister or the Secretary
- share data with external agencies.

These outcomes will be included in future reports.

Monitoring medication in the community

The Board ensures any unused voluntary assisted dying medication in the community is returned to the statewide pharmacy.

When not all the medication is used, or the patient no longer requires it, a nominated contact person must return any remaining medication. It is an offence not to do so within 15 days.

As per the Act, the Board finalised arrangements with Births, Deaths and Marriages to notify us of the death of someone with a voluntary assisted dying permit. This allows us to liaise with the contact person to return the medication, even in instances where the permit holder has died from other causes.

The contact person will also be asked to provide feedback regarding the process to help us identify areas for improvement.

Launching the Voluntary Assisted Dying Portal

To ensure submission of the required forms is secure, confidential and complete, the Board oversaw the build of the online Voluntary Assisted Dying Portal.

Launched in April 2019, this is a secure online platform where registered medical practitioners can complete, submit, view and download the 12 forms required under the Act and the Voluntary Assisted Dying Regulations 2018. It is an intuitive process, with automated email notifications and downloadable copies for medical files.

Registering medical practitioners

Following the launch of the portal, medical practitioners commenced registering for and were granted access to the portal.

To do this, they needed to:

- pass the approved voluntary assisted dying training
- provide evidence of their identity, fellowship with a specialist medical college or vocational registration.

Supporting reporting requirements

The portal was designed to allow the Board to review each voluntary assisted dying case, as well as run statewide data reports.

The forms also collect some voluntary information to give us greater insight into user demographics and experience, allowing us to make recommendations about quality and safety improvements.

Sharing information with external agencies

Some level of access was also given to authorised users to allow them to complete required actions under the Act. These users include:

- drugs and poisons officers (employees of the Department of Health and Human Services)
- secretariat (employees of Safer Care Victoria)
- the statewide pharmacy service (employees of Alfred Health)
- members of the Voluntary Assisted Dying Review Board.

The data we collect

The Board receives information about the disease, illness or medical condition of persons who met the requirements of the eligibility criteria, demographic information, and other insights.

The Board will report more of this information in the future.

We cannot yet publish detailed data, as numbers are small and the information could be used to identify patients, doctors and other participants.

The data we intend to publish in future years can be found at **Appendix 3**.

Recommending improvements to how voluntary assisted dying runs

Under the Act, the Board may make recommendations to improve the operation of the voluntary assisted dying law.

In this reporting period, the Board has not made any recommendations.

LOOKING AHEAD

The Board will report again by February 2020. We anticipate we will be able to report more detailed data, depending on the volume of cases we see.

We may also be able to include outcomes of the Board's review process, including compliance with the Act, referrals made to other agencies, quality and safety issues, and insights regarding the voluntary assisted dying process.

In the next six months, we will also progress the development of the Board's research function. The Board will adopt a research partnership model, allowing the Board to commission research, and for researchers to request deidentified data.

Appendix 1

FUNCTIONS AND POWERS OF THE BOARD

The functions and powers of the Board are detailed in the Act:

- (a) To monitor matters related to voluntary assisted dying;
- (b) To review the exercise of any function or power under the Act;
- (c) To provide reports to each House of the Parliament on the operation of the Act and any recommendations for the improvement of voluntary assisted dying;
- (d) To promote compliance with the requirements of the Act by the provision of information in respect of voluntary assisted dying to registered health practitioners and members of the community;
- (e) To refer any issue identified by the Board in relation to voluntary assisted dying that is relevant to the following persons or bodies:
 - (i) The Chief Commissioner of Police;
 - (ii) The Registrar of Births, Deaths and Marriages;
 - (iii) The Secretary of the Department of Health and Human Services;
 - (iv) The State Coroner;
 - (v) The Australian Health Practitioner Regulation Agency.
- (f) To promote continuous improvement in the quality and safety of voluntary assisted dying to those who exercise any function or power under the Act;

- (g) To conduct analysis of, and carry out research in relation to, information or forms given to the Board in accordance with the Act;
- (h) To provide information about voluntary assisted dying, and other matters identified by the Board in the performance of a function under the Act;
- (i) To collect, use and disclose forms and information provided in accordance with the Act for the purposes of carrying out a function of the Board;
- (j) To consult and engage with any of the following persons in relation to voluntary assisted dying:
 - (i) The Victorian community;
 - (ii) Relevant groups or organisations;
 - (iii) Government departments and agencies;
 - (iv) Registered health practitioners who provide voluntary assisted dying services.
- (k) To provide advice to the Minister or the Secretary in relation to the operation of the Act; and
- (I) To provide reports to the Minister or the Secretary in respect of any matter relevant to the functions of the Board as requested.

Appendix 2

TERMS OF REFERENCE

The terms of reference are due for annual review in August 2019.

Overview

The Voluntary Assisted Dying Review Board was established by the *Voluntary Assisted Dying Act* 2017 (the Act) to review every case of voluntary assisted dying, report on the operation of voluntary assisted dying and inform system-wide quality and safety improvements.

Voluntary assisted dying is a sensitive topic that attracts a lot of attention and interest, and is subject to a wide range of viewpoints, concerns and options. One of the key roles of the Board is to reassure the public that they are bringing to bear their expertise and experience to oversee the implementation and operation of voluntary assisted dying activity in a safe and compassionate way.

Functions and powers

- Monitor matters related to voluntary assisted dying.
- Review each case of voluntary assisted dying and each assessment for voluntary assisted dying to ensure they comply with statutory requirements.
- Promote compliance with statutory requirements by providing information about voluntary assisted dying to registered health practitioners and members of the community.
- Collect information and data, setting out additional data to be reported.
- Request additional information from medical practitioners or health services.
- Refer potential breaches of statutory requirements to the appropriate investigative authority, including the Chief Commissioner of Police, the Registrar of Births, Deaths and

Marriages, the Secretary of the Department of Health and Human Services, the State Coroner and the Australian Health Practitioner Regulation Agency.

- Report to Parliament on the operation of the Act and any recommendations to improve voluntary assisted dying.
- Provide reports and advice to the Minister or Secretary in respect to the operation of the Act or matters relevant to the functions of the Board as requested.
- Monitor, analyse, consider and report on matters relating to voluntary assisted dying.
- Support research relating to voluntary assisted dying.

Principles

Extract from the S5 of the Act:

- A person exercising a power or performing a function or duty under this Act must have regard to the following principles
 - a) every human life has equal value;
 - b) a person's autonomy should be respected;
 - c) a person has the right to be supported in making informed decisions about the person's medical treatment, and should be given, in a manner the person understands, information about medical treatment options including comfort and palliative care;
 - d) every person approaching the end of life should be provided with quality care to minimise the person's suffering and maximise the person's quality of life;
 - e) a therapeutic relationship between a person and the person's health practitioner should, wherever possible, be supported and maintained;

- f) individuals should be encouraged to openly discuss death and dying and an individual's preferences and values should be encouraged and promoted;
- g) individuals should be supported in conversations with the individual's health practitioners, family and carers and community about treatment and care preferences;
- h) individuals are entitled to genuine choices regarding their treatment and care;
- there is a need to protect individuals who may be subject to abuse;
- j) all persons, including health practitioners, have the right to be shown respect for their culture, beliefs, values and personal characteristics.

Membership

The Board consists of the Chairperson, Deputy Chairperson (optional) and members appointed by Ministerial order. Inaugural Board members hold office for six years, as specified in the instrument of appointment. Members are then eligible for reappointment for three years. A member may resign in writing (signed by the member) to the Minister. The Minister may at any time remove a member of the Board from office.

Responsibility and behaviours

Members are required to act in accordance with behaviours expected of senior public officials and to acquit their executive, legal and regulatory responsibilities. Members are expected to meet the obligations detailed in the Code of Conduct for Directors of Victorian Public Entities, and 'Welcome to the Board: Directors' Guide to Public Entity Governance'. Each member is required to complete a declaration of private interests annually.

Furthermore, members are expected to:

- maintain a thorough understanding of, and comply with, the terms of reference and the expectations of members in meetings
- embrace the solidarity principle that applies once a recommendation has been made, and demonstrate collective accountability and responsibility for the direction taken
- demonstrate active listening and provide each member with the opportunity to speak and ask questions
- ensure that a diverse range of views and perspectives are considered, and explicitly and respectfully engage with differing viewpoints
- facilitate an environment for members to behave to the highest standards, and provide appropriate ways to report and act on inappropriate behaviours.

Chairperson

In addition to the expectations for members, the role of the Chairperson is to lead the Board to achieve its objectives and execute its responsibilities in line with its terms of reference.

The responsibilities of the Chairperson are to:

- understand the Board terms of reference and coordinate efforts to meet and uphold them
- ensure the Board's actions are aligned with the Act
- manage Board meetings, including:
 - working with the secretariat to set the meeting schedule
 - calling special meetings as required
 - working with the secretariat to ensure appropriate preparation and consultation has been undertaken to inform the agenda and papers

- facilitate Board meetings, including keeping discussion on track; ensuring all members have an opportunity to express their views; seeking consensus/agreement on issues; announcing results, actions, and follow up to be taken by whom and by when, and; closing meetings
- approve minutes (prepared by the Board secretariat) for circulation to members
- be the main liaison for the Board with the implementation taskforce in conjunction with the Board secretariat
- induct new members and make sure they are aware of the terms of reference of the Board.

Secretariat

Safer Care Victoria provides the secretariat function for the Board.

The role of the secretariat is to support the smooth operation of Board proceedings, and ensure members are fully informed and prepared. It is responsible for:

- managing the meeting schedule and preparing the agenda, in consultation with the Board members, for approval by the Chairperson
- confirming appropriate consultation has been undertaken with the relevant groups across the department or external agencies prior to circulation of any papers
- compiling supporting papers, and ensuring their timely distribution
- arranging for departmental staff and advisers to provide advice, and if required, to attend meetings of the Board to present this advice;
- recording attendance and apologies for each meeting

- taking minutes of meetings, including preparation of the minutes, circulation of the draft for comment, and finalisation of the minutes in consultation with the Chairperson
- with the Chairperson, ensuring Board actions, owners and timelines are identified in minutes, and are followed up and communicated appropriately
- ensuring members complete an annual declaration of private interests.

Furthermore, the secretariat works with the Board and the implementation taskforce to establish and maintain operational systems to support the functions of the Board, including the following functions:

- Liaise with the taskforce on behalf of the Board.
- Liaise with relevant external agencies.
- Establish and maintain Board processes for the review of voluntary assisted dying cases.
- Establish and maintain referral process for non-compliant medical practitioners to the relevant regulatory agencies.
- Manage the voluntary assisted dying 'portal', including quality control processes and online reporting.
- Coordinate information sharing between the Board and Births, Deaths and Marriages.
- Undertake contact with medical practitioners and contact persons to promote compliance with the Act.
- Liaise with the department's drugs and poisons branch on the process of assessing applications to prescribe the voluntary assisted dying substance.

- Maintain the register of medical practitioners who have undertaken the voluntary assisted dying training and monitor the adequacy and currency of participating medical practitioners qualifications and registration status.
- Coordinate the periodic reporting process, including drafting, providing analysis of voluntary assisted dying data, publication and provision to the clerk of each house of the parliament within statutory time limits.
- Coordinate and respond to reporting requests from the Secretary or Minister as required.
- Support the review of clinical guidance, approved assessment training, medication protocols, model of care and consumer information.
- Coordinate the Board's involvement in a collaborative research program in partnership with Safer Care Victoria and the department.

Meeting arrangements

Frequency of meetings

Meetings are held monthly. Special meetings may be convened as required. The Chairperson, or in the absence of the Chairperson, the Deputy Chairperson, must preside over meetings.

A majority of the members of the Board currently holding office constitutes a quorum. Members should seek to attend at least 75 per cent of regular meetings.

The Act states the Board may regulate its own proceedings.

The secretariat will seek to circulate meeting agendas and papers five working days prior to meetings and circulate meeting draft meeting minutes five working days following meetings. Members will then have five working days to provide comment on the minutes.

Members who are unable to attend a Board meeting should notify the secretariat at least one working day prior to the meeting.

Reporting

The Board's reporting requirements are mandated in the Act.

For the first two years of operation, the Board will provide Parliament with a report on the operation of the Act as soon as practicable after 30 June and 31 December each year. After two years, an annual report is required to be provided no more than three months after the end of the financial year.

The report may include any deidentified information of a person, who during the reporting period accessed or requested access to voluntary assisted dying under the Act. The report may also include any recommendations on any systemic voluntary assisted dying matter identified by the Board during the reporting period.

The report must not include any information (including deidentified information) that the Board considers would prejudice any criminal proceeding or investigation, civil proceeding, or any proceeding in the Coroners Court of Victoria.

The Board is also required to respond to reporting requests from the Secretary or Minister as required.

Appendix 3

FUTURE REPORTING MEASURES

	Status
First assessment	Eligible
	Ineligible
Consulting assessment	Eligible
	Ineligible
Permit applications to DHHS Secretary	
Self-administration permit	Approved
	Not approved
Practitioner administration permit	Approved
	Not approved
Medications dispensed	Self-administration
	Practitioner administration
Notification of death from Births, Deaths and Marriages	Person subject to voluntary assisted dying permit but medication was not taken (neither self-administered or practitioner administered)
	Person subject to a self-administration permit and accessed voluntary assisted dying by taking the medication (self-administration)
	Person subject to a practitioner administration permit and accessed voluntary assisted dying by being administered the medication
Withdrawn cases	This may include cases that commenced but were not completed. For example, a person died prior to completing all steps in the process

More information

bettersafercare.vic.gov.au/vad

Feedback

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